DOCUMENT RESUME

ED 292 272 EC 202 055

TITLE Building Bridges for Communication: A Reference Book on Communication, Terms, Laws, and Other Information Relating to Persons with Disabilities.
INSTITUTION Governor's Planning Council on Developmental Disabilities, Springfield, Ill.
PUB DATE Jun 87
NOTE 60p.
PUB TYPE Guides - Non-Classroom Use (055) -- Reference Materials - Directories/Catalogs (132) -- Reference Materials - Vocabularies/Classifications/Dictionaries (134)

EDRS PRICE MF01/PC03 Plus Postage.
DESCRIPTORS *Advocacy; Definitions; *Disabilities; Federal Legislation; Handicap Discrimination; Interpersonal Relationship; *Normalization (Handicapped); Perspective Taking; Public Agencies; *Social Cognition; *Social Networks; State Agencies; State Legislation
IDENTIFIERS Illinois

ABSTRACT

Developed by the Illinois Governor's Planning Council on Developmental Disabilities, this guide is intended to help parents and other laypersons communicate more knowledgeably and effectively with professionals who work with handicapped persons, as well as with handicapped individuals themselves. Section I offers suggestions for interpersonal communication with disabled persons and provides guidelines for writing and speaking about disabled persons in print and visual media. Subsequent sections include a glossary of disability-related terms, brief explanations of relevant federal and state statutes, and information on executive and elective offices, state agencies, and commissions in the state of Illinois. Names and addresses of national and state advocacy and consumer organizations, a glossary of disability-related acronyms, and agency toll-free numbers conclude the document. (JW)

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BUILDING BRIDGES FOR COMMUNICATION

A Reference Book on Communication, Terms, Laws, and Other Information Relating To Persons with Disabilities

Illinois Governor's Planning Council
on Developmental Disabilities

JUNE, 1987

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CHAIRPERSON

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INTRODUCTION

"You want to talk or write to or about someone with a disability. You know the person is more important than the disability. You want to build bridges not erect barriers." Often the general public is hesitant to communicate with persons who have disabilities because of fear or embarrassment usually due to lack of knowledge about disabilities in general or misconceptions about these persons due to preconceived notions.

"How do you, a layperson - parent, relative, friend or teacher - find your way through the maze of jargon that confronts you when you talk with professionals? How do you know what all those acronyms stand for - let alone find the good programs they represent? And how do you know what federal and state legislation has been passed to assist people with disabilities?" Language plays a critical role in improving public perception of people with disabilities. This book offers suggestions for appropriate communication for conversation, written or visual portrayal.

Often the jargon used in the field hinders peoples attempts to understand their neighbors who have disabilities A glossary of terms frequently used in the field with definitions in lay terms follows this section. The reader should note that the usage of terms such as "handicap" "disabled person" are only used when stated as such in law and rule/regulation.

A compendium of relevant federal and state laws affecting persons with disabilities are provided in Section IV. Frequently, reference is made to various laws which provide protection of rights, and/or specific services or entitlements for persons with disabilities.

Finally, the handbook offers a listing of national and state advocacy and consumer organizations for persons with disabilities and a listing of toll free telephone numbers to contact for additional information or assistance.

This book has been designed for you and is not intended to be all encompassing. It will, however, serve as a reference to enhance individual basic awareness about persons with disabilities. We hope you find it useful.

ACKNOWLEDGMENTS

The Council wishes to thank the numerous persons who contributed to the development of his book in terms of material, comments and suggestions.

In particular, the Council thanks the South Carolina Council on Developmental Disabilities and the New York State Senate Select Committee on the Disabled for the use of their documents entitled Looking At People--Communication With And About People With Disabilities and Coming To Terms With Disabilities. Each of these provided valuable guidance and material for People With Disabilities: A Hand book on Communication, Terms and Laws Relating to Persons With Disabilities. Also, in the Glossary Section, we have included, where referenced, terms and explanations taken from the National Rehabilitation Association's glossary of terms and usage related to disabilities.

We would also like to extend our appreciation to Mari Ana McAnarney our secretary for the time spent in typing this document.

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ILLINOIS GOVERNOR'S PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES

The Illinois Governor's Planning Council on Developmental Disabilities was created by Governor's Executive Order #2 (1985) pursuant to the Public Law 95-602 Developmental Disabilities Assistance and Bill of Rights Act and as amended by Public Law 98-527, Developmental Disabilities Act of 1984.

The members of the Council, appointed by the Governor are representative of consumers with developmental disabilities, parents, guardians or immediate relatives of persons with developmental disabilities, and representatives of governmental and nongovernmental agencies and organizations concerned with services for persons with developmental disabilities. The Council through its role of advocate, is the forum to ensure that Illinois citizens with developmental disabilities receives the care, treatment and other services necessary to enable them to reach their maximum potential.

The mission of the Council is that of a leadership role in shaping policy affecting persons with developmental disabilities and those at risk of developmental disabilities in Illinois. In an advisory capacity, the Council presents to the Governor, the Illinois General Assembly, and state agencies public policy issues and recommendations that set forth a policy stance concerning services for persons with developmental disabilities. The Council generates public policy research that includes a thorough analysis of current practices, national and state priorities, valid data, and programmatic and fiscal impact statements to affect policy shaping and to act as a catalyst through strong interagency collaboration.

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SECTION I

COMMUNICATION

Communicating in Person

Many persons without disabilities inadvertently address persons with disabilities as if they are speaking to a nonentity or through a third person. The following are points which should guide communication:

- Give and maintain eye contact.
- Talk to the person, especially if using an interpreter.
- Speak in your usual tone of voice and with your usual voice inflection.
- If you do not understand someone, ask the person to repeat the statement. If you still do not understand, tell them so.
- If appropriate, use gestures and sign language or interpreters.
- When speaking to someone who is developmentally delayed, use clear, concise language and avoid complex sentences. Use simple language, however not childish language.
- Sometimes people with developmental or communicative disabilities may need a little more time to respond. Wait for their answers; do not speak for them.
- When talking with a person who uses a wheelchair, try to sit across from him/her at eye level.
- Ask if assistance is needed, rather than assume it is. If the person does desire assistance, he/she will tell you what would be helpful.
- Acknowledge the natural curiosity and occasional awkwardness that may develop in social situations involving non-disabled individuals and individuals with disabilities. Where appropriate, address positive moments in which curiosity can be satisfied and in which awkwardness can be lessened.

Communicating in Print

The following are points of reference when referring to persons with disabilities.

- Emphasize the uniqueness and worth of all individuals rather than differences between people.
- Do not refer to a disability unless it is crucial to your purpose.
- Keep the individual in perspective; avoid emphasizing the disability to the exclusion of individual qualities and achievements.
- Avoid portraying or addressing persons with disabilities who are successful as superhuman. This implies that it is unusual for persons who are disabled to have talents or unusual gifts.
- Do not sensationalize a disability by saying "afflicted with" or "victim of," etc. Instead, say "person who has multiple sclerosis," "person who had polio," etc.
- Avoid labeling persons into groups, as in "the disabled," "the deaf," "the retarded." Instead say "people who are deaf," "persons with disabilities or retardation."
- Initials are all right to describe a condition but not a person (C.P., M.D., etc.). It is better to say "cerebral palsy," "muscular dystrophy," etc.
- Avoid using emotional descriptors such as "unfortunate" and "pitiful." Emphasize abilities, such as "uses a wheelchair" rather than "confined to a wheelchair."
- Avoid implying disease when discussing disabilities. A disability such as Parkinson's disease may have been caused by an illness, but it is not a disease itself, nor is the person necessarily chronically ill. Persons with disabilities should not be referred to as "patients" or "cases" unless they are under medical care in medical settings.
- Show people with disabilities participating in activities that includes them as part of society and in interaction with non-disabled individuals in mutually beneficial ways.

- Show individuals with a disability doing something independently or for someone else and as participants and decision-makers.

- Do not assume a person has other disabilities when one disability may be obvious.

- If the individual's disability is germane to your story, ask the individual about it directly, rather than asking someone else.

- Information should be provided to the public about prevention and treatment of impairments that lead to disabilities, as well as the availability of services for people with disabilities and their families.

- As with most articles that appear in print, the individuals should be informed of your purpose and plans. Frequently, persons with disabilities and their families are sensitive about their situation. Consent should be obtained where necessary and confidentially respected when requested.

Communicating Visually

The following points provide guidance when presenting information regarding persons with disabilities.

- When using visual material with a project (slides, pictures, tapes, etc.), actual photographs, used with an individual with a disability's permission, are preferable (in most cases) to drawings.

- Avoid stereotyped portrayal of individuals with disabilities such as dark glasses on a person with a visual impairment or antique aids (i.e., cane or wheelchairs in place of state of the art equipment)

- Show pictures or photographs of individuals with disabilities in their usual environment and engaged in common activities.

- Do not present an individual visually in order to portray the disability. Use photographs or drawings to personalize the individual.

(The preceding material was taken from Looking at PEOPLE communications with and about people with disabilities, South - Carolina Developmental Disabilities Council)

SECTION II

GLOSSARY

Able-Bodied

The preferred term for describing persons without disabilities. The word "normal" is often used as a synonym for able-bodied. (National Rehabilitation Association)

Accessibility

Refers to the degree to which persons with disabilities can participate in activities of daily living such as employment, recreation, housing, transportation and education without limitations or denial due to architectural and/or attitudinal barriers. Accessibility is a requirement for all projects receiving federal funds.

Active Treatment

Ensures that services to persons in Intermediate Care Facilities for the Developmentally Disabled (ICFDD) in both the public and private sectors provides active treatment for all residents. Active treatment is defined as "services directed toward: (1) The acquisition of developmental, behavioral, and social skills necessary for the client's maximum possible individual independence; and (2) For dependent clients where no further positive growth is demonstrable, the prevention of regression or loss of current optimal function status." (Health Care Financing Administration)

Adaptive Behavior

The degree to which a person's developmental level parallels the expected standards for independence and social functioning of his/her age and cultural background.

Advocacy

A system, independent of service providers, to protect persons with developmental disabilities by use of legal, administrative and other remedies. Advocacy can also be one person intervening on the behalf of another, with permission, when the other person is unable to successfully act in their own behalf. Self advocacy is based upon the premise that individuals who have adequate information and skills can be effective spokespersons for themselves.

Affirmative Action

The hiring and promoting of qualified individuals regardless of race, sex, national origin or ancestry, providing the individual can perform at the minimum accepted standards.

Aging-Out

Terminology generally used when referring to secondary special education students exiting public schools to the post-school adult service delivery system.

AIDS (Acquired Immune Deficiency Syndrome)

Causes the body to lose its natural defenses against disease leaving it open to illnesses ranging from mild infections to life-threatening conditions.

Alzheimer's Disease

A progressive, degenerative disease that can cause memory loss, confusion, inability to make decisions, difficulty in speech and movement and loss of basic skills.

For more information, contact:

-- Alzheimer's Disease and Related Disorders
1-800-621-0379
(For additional toll free numbers see Section VII)

Ambulatory

Ability to walk or move independently; also refers to persons who with assistance or adaptive devices are mobile.

Amputee

A term which refers to a person who has had a limb removed or part of a limb removed from the body.

Anti-Convulsant

A chemical agent that arrests or prevents convulsions or seizures.

Aphasia

A term that can apply to expressive and receptive loss of language and speech skills.

Architectural Barriers

Term which refers to a building's design which limits or prohibits access by mobility impaired persons.

Arthritis

Inflammation of a joint which affects muscles, ligaments, tendons, joints and other body parts which have different symptoms, patterns and treatment.

Assessment

Evaluation of an individual's performance or developmental level which can be used in program planning.

Ataxic

The loss or lack of muscular coordination.

Athetoid

The constant, slow, involuntary movement of the extension and flexing of extremities.

At Risk

A term generally used to address an individual who has a high potential to have a developmental disability; most often used in describing infants who due to pre or postnatal factors may be at risk of having a developmental disability.

Attendant/Personal Care Assistant

The assistance provided to an individual in activities of daily living, communication, mobility and management of other activities, as needed.

Audiologist

An individual who by training is licensed and certified to measure types and degrees of hearing loss and who works to prevent hearing disorders.

Autism

A term for describing a condition that may be manifested before a person is 30 months of age, may be caused by physical disorders of the brain, and; is characterized by uneven intellectual development and a combination of disturbances in the rates and language, and speech development. This syndrome is further evidenced by abnormal response to sensory stimuli, problems in developing social relationships, and ritualistic and compulsive behavior. (Illinois Revised Statutes, Chapter 91 1/2, Section 1-106 the Mental Health and Developmental Disabilities Code).

Barrier Free

A building or program that is totally accessible to persons with mobility limitations, or persons with hearing and vision impairments. Can also refer to the absence of attitudinal barriers.

Behavioral Disorder

For educational purposes, a child who exhibits an affective disorder and/or adaptive behavior which significantly interferes with his/her learning and/or social abilities.

Behavior Modification

The shaping of an individual's environment through systematic application of principles of learning in shaping behavior to minimize or eliminate undesirable behavior and to emphasize and reinforce positive and appropriate behavior.

Blind

Total loss of vision; the term is not appropriate to describe persons with partial vision or sight.

For more information, contact:

-- National Library for Blind & Physically Handicapped
Washington, D.C.
1-800-424-8567
(For additional toll free numbers see Section VII)

Braille

A tactile approach to reading and writing for persons who are blind or visually impaired. A combination of raised dots on paper is the most widely used method of communication for these individuals.

Case Coordination

Services to persons with developmental disabilities as will assist them in gaining access to needed social, medical, educational, and other services. Such term includes (i) follow-along services which ensure, through a continuing relationship, lifelong if necessary, between an agency or provider and a person with a developmental disability and the person's immediate relatives or guardians, that the changing needs of the persons and the family are recognized and appropriately met; and (ii) coordination services which provide to persons with developmental disabilities support, access to (and coordination of) other services, information on programs and services, and monitoring of the person's progress. (P.L. 98-527)

Cardiovascular Disease

A general category which encompasses a number of different problems of the heart and circulatory system.

Centers for Independent Living

A program federally supported under the Rehabilitation Act of 1973, which provides a wide range of services to persons with disabilities. Services can include: intake counseling; information and referral; advocacy; training in independent living skills; housing and transportation referral and assistance; and training of personal care assistants. Allows persons to live independently of their families and provides assistance in securing employment. The Centers are located in communities and are governed by consumers.

Cerebral Palsy (CP)

An alteration in the movement of the body due to an injury or a disorder of the central nervous system. It is manifested by an unsteady gait and may impair speech. There are three main types: spastic--uncoordinated muscle movement or opposing contractions, athetoid--involuntary, repetitive movements of the extremities, head and may affect speech, and ataxic--loss of movement and occasionally balance.

Child Care Institution (CCI)

Facilities which serve approximately 50-100 children with developmental disabilities. These facilities are licensed by the Illinois Department of Children and Family Services and funded through the Illinois Department of Mental Health and Developmental Disabilities.

Chronic Care

Level of care for individuals who require intensive care in terms of facilities, services or skills which only a hospital or other specialized facility can provide.

Client Assistance Program (CAP)

A program to assist people with disabilities in understanding and securing the benefits and programs available under the Rehabilitation Act (Rehabilitation Act Amendments of 1984, P.L. 98-221).

For more information, contact:

-- Client Assistance Program
1-800-641-3929

Communication Disorder

A disorder in one or more of the processes of speech, hearing or language which interferes with the ability to speak, understand or use language. Such disorders may be developmental or acquired, may range from mild to severe, and may or

may not be associated with a disabling condition.

Community Living Facility

Community-based living arrangement, housing, on the average 20 adults with disabilities 18 years of age and older. These facilities are licensed by the Illinois Department of Public Health and funded by the Illinois Department of Mental Health and Developmental Disabilities Purchase of Care System.

Community Mental Health Center (CMHC)

A center which provides a full range of mental health services including inpatient and outpatient care; community services including consultation and education; diagnosis; rehabilitation; training; and research evaluation.

Community Residential Alternative (CRA)

A group home for 8 or fewer adults with developmental disabilities who are unable to live independently but are capable of community living if provided with an appropriate level of supervision, assistance and support services. A community residential alternative may provide training and guidance to residents in the skills of daily living and shall provide opportunities for participation in community activities.

Competency Test

An evaluation of an individual to determine whether he/she is legally capable of making choices and legally responsible for his/her actions. Applies to persons with disabilities such as mental illness or mental retardation.

Congenital Disability

The correct term for describing a disability which has existed since birth. The often-used term "birth defect" is considered inappropriate when used to describe human beings. (National Rehabilitation Association)

Convulsion

The involuntary contractions of muscles resulting from abnormal cerebral stimulations which may occur with or without loss of consciousness. Types of convulsions are: clonic--alternating contraction and relaxation of muscles; and tonic--sustained rigidity.

Crisis Intervention

A term generally referring to emergency services of an intensive nature to alleviate stressful situations.

Curb Cuts

A term used to describe physical alterations to streetside curbs to enable persons with mobility limitations to ascend and descend from sidewalk to street.

Cystic Fibrosis

A condition in which mucus secretions obstruct body organs especially the lungs and pancreas, -- a common and hereditary condition in childhood which is usually fatal.

For more information, contact:

-- National Cystic Fibrosis Foundation
1-800-344-4823

Deaf

The term correctly used to describe a person with a total hearing loss. It is not considered appropriate for describing a person with partial hearing. Such persons are more accurately described as having a partial or severe hearing loss or a hearing impairment. (National Rehabilitation Association).

For more information, contact:

-- Center for the Deaf
1-800-468-9211

Developmental Center

A term generally applied to state operated facilities where persons with developmental disabilities or mental retardation reside.

Developmental Disability

A severe, chronic disability of a person which is attributable to a mental or physical impairment or combination of mental and physical impairments. This condition is manifested before the person attains age twenty-two and is likely to continue indefinitely. It results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. The disability reflects the person's need for a combination and sequence or special interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated (P.L. 98-527) **OR**

...a disability which is attributable to: (a) mental retardation, cerebral palsy, epilepsy or autism; or to (b) any other condition which results in an impairment similar to that caused by mental retardation and which requires services similar to those required by mentally retarded persons. Such disability must originate before the age of 18 years, be expected to continue indefinitely, and constitute a substantial handicap. (Illinois Revised Statutes, Chapter 91 1/2, Section 1-106, Mental Health and Developmental disabilities Code)

Developmental Training

Focus of this program is upon development of skills for daily living or for independent living through repetitive learning activities in such areas as motor, dressing and grooming, toileting, eating, language, and reducing maladaptive behavior for persons with developmental disabilities. This program is supported by the Department of Mental Health and Developmental Disabilities, and through the Department of Public Aid.

Deinstitutionalization

A term which generally refers to the discharge of persons with developmental disabilities or mental illness from State operated facilities.

Disability

A term generally referring to a physical and/or mental impairment.

Discrimination

The ability to tell the difference or sameness between at least two objects or stimuli. Also frequently used when a person with a disability is denied access to a program or building due to environmental barrier(s).

Down Syndrome

A genetic disorder associated with mental retardation, which results from an excess of chromosomes that alter the ordinary development of the body and brain.

For more information, contact:

-- National Down Syndrome Society
1-800-221-4602

Due Process

A term which describes a principle of law which guarantees an opportunity to protest, to be heard, to be informed and to give consent prior to governmental action. Most often used when referring to special education; this protection of rights would also be applicable in the areas of rehabilitation, employment and others.

Dysfunction

Partial disturbance or an impairment of a body function.

Dyslexia

A term used to describe an impairment of the ability to read due to obvious language difficulties, (commonly referred to as a learning disability). Sometimes characterized by reversal of letters or improper letter sequencing.

For more information, contact:

-- Orton Dyslexia Society
1-800-222-3123

Early Intervention

A wide range of educational and/or medical services delivered to infants and young children with disabilities or at risk of disabilities.

Early Periodic Screening, Diagnosis and Treatment Program (EPSDT)

A program which screens, identifies, and provides health care and related needs of children who are recipients of Aid to Families with Dependent Children.

Educable

A term used in special education which refers to the classification of a child's intellectual development, mental capacity, academic achievement and adaptive behavior as mild or moderate mental retardation.

Emotionally Disturbed

A term often used in education which refers to the inability to control emotions and behavior within an acceptable range.

Encephalitis

Any condition which causes "inflammation of the brain"--usually due to viral infections causing damage to one or more parts of the brain. Resultant brain dysfunction can cause learning and behavior disorders.

Epilepsy

A neurological condition or disorder of the central nervous system marked by seizures caused by electrical discharges within the brain. The most common types of seizures are petit mal--loss of consciousness for a few seconds; grand mal--lasting one to three minutes and generally affecting the entire body; and psychosomatic--generally characterized by staring or a no-or-confused response. Symptoms vary among individuals. Epilepsy is almost always controllable by medication.

For more information, contact:

-- Epilepsy Foundation of America
1-800-EFA-1000
(For additional toll free numbers see Section VII)

Evaluation

An appraisal of an individual's functioning level in intelligence, education, vocational, physical and behavioral areas.

Exceptional

A term generally used in special education to refer to a student's characteristics which interfere with their ability to learn.

Family Home Maintenance

Direct staff resources to persons who require intensive habilitation or crisis behavior management to prevent extrusion from the home or to secure residence in a less restrictive living arrangement. This service is funded through the Illinois Department of Mental Health and Developmental Disabilities' Purchase of Care System.

Family Support

Services and/or cash assistance provided to families who care for a family member with developmental disabilities in their home. Such assistance is intended to prevent or delay unnecessary out-of-home placement of the individual with developmental disabilities or allow for return home from an alternative residential placement, while enhancing the family's ca-

pacity to provide home-based care.

Fine and Gross Motor

Terms used to describe small and large muscle group activity. For example, fine motor activities involve the hands in drawings, writing, whereas gross motor would include activities such as rolling, running or jumping.

Foster Care

Care provided to a child or an adult by non-biological parents, often providing training for the individual. For children, these homes receive financial support from the Illinois Department of Children and Family Services. The Illinois Department of Mental Health and Developmental Disabilities supports this type of residence for adults through the purchase of care program.

Free Appropriate Public Education

Federal Public Law 94-142, the Education of the Handicapped Act, mandates that all children regardless of disability, are entitled to a free appropriate public education. This means that special education and related services are to be provided at public expense and in the least restrictive environment (LRE) for eligible children and must meet the specifications of the individual education plan (IEP).

Genetic Counseling and Testing

The test and assessment of the reproductive risks of inherited or genetically transmitted diseases and syndromes.

Group Home

A small residential living arrangement in the community for persons with mental retardation or with disabilities, generally for eight or fewer persons.

Guardianship

Legal status of a child or an adult who has been adjudicated incompetent by a court of law. Limited guardianship means no finding of legal incompetence, but does restrict specific decisions the individual may make.

Habilitation

An effort directed toward the alleviation of a developmental disability or toward increasing a developmentally disabled person's level of physical, mental, social or economic functioning. Habilitation may include, but is not limited to, diagnosis, evaluation, medical services, residential care,

day care, special living arrangements, training, education, sheltered employment, protective services, counseling and other services provided to developmentally disabled persons by developmental disabilities facilities. (Illinois Revised Statutes, Chapter 91 1/2, Section I-III)

Handicap

Often used as a synonym for disability. Use has become less acceptable, and should only be used when citing laws and regulations.

Hard of Hearing

A residual hearing loss that with adaptations or training can still allow for hearing and speech to some degree.

Hearing Impairment

A term used to refer to the entire range of auditory impairment from deaf to hard of hearing.

For more information, contact:

-- Hearing Helpline - Better Hearing Institute
1-800-424-8576
(For additional toll free numbers see Section VII)

Home Individual Program (HIP)

Homes located in the community where no more than two adults or children with disabilities live under the supervision of a couple. Individualized programs in the areas of education, independent living and community utilization skills and others are provided. HIP programs are approved and funded through the Illinois Department of Mental Health and Developmental Disabilities.

Home Services

Services to individuals in their own homes by personal care assistants, chore/housekeepers or homemakers in daily activities to prevent unnecessary institutionalization. This program is supported and provided by the Illinois Department of Rehabilitation Services.

Human Service System

A generic term generally used to describe the network or service system that provides for support, day programs, employment, and residential services for persons with disabilities.

Hydrocephalus

A term which describes a condition where excess fluid in the cranial cavity causes pressure on the brain and results in an enlarged head. This condition can cause mental retardation if medical treatment is not received.

Hyperactivity

A term which describes behavior which is characterized by excessive activity or movement.

Independent Living Skills

A term used to describe practical skills needed to function in society. Sometimes referred to as activities of daily living. Generally means dressing, eating, and use of money skills.

Individual Written Rehabilitation Program (IWRP)

Term used in the field of rehabilitation (Rehabilitation Act) which states that a IWRP shall be developed for persons with disabilities on the basis of a determination of employability designed to achieve the vocational objective of the individual.

Individualized Education Program (IEP)

A term used in education which means a written statement for a school age child that includes the following components: statement of the child's present levels of educational performance; statement of annual goals, including short term instructional objectives; statement of the specific special education and related services to be provided to the child, and the extent to which the child will be able to participate in regular educational programs; projected dates for initiation of services and the anticipated duration of the services; and appropriate objective criteria and evaluation procedures and schedules for determining, on at least an annual basis, whether the short term instructional objectives are being achieved. (Education of the Handicapped Act, P.L. 94-142)

Individual Habilitation Plan

A term generally used in the field of developmental disabilities that describes the habilitation goals; a projected timetable for their attainment; the services to be provided; the role of the family in the implementation of the plan; and the name of the person responsible for supervising the habilitation program of an individual with a disability or disabilities. (Illinois Revised Statutes, Chapter 91 1/2, Section 4-309)

Institutionalization

A term used to describe placement in a state or private setting of a long term nature; generally housing 100 or more persons.

Integration

Access to all aspects in the community setting through the removal of legal, social or other barriers previously imposing segregation.

Intermediate Care Facility for the Developmentally Disabled (ICFDD)

Residents of these facilities receive specialized programming in areas such as independent living skills, self-care, behavior management and support services. Average facility size is 70-100 adults, 18 years of age and older. Intermediate Care Facility for the Mentally Retarded (ICFMR) a classification at the federal level for these specialized facilities for persons who are mentally retarded or developmentally disabled. Facilities and beds certified as ICFMR allows the state to capture 50% reimbursement of total cost of care for each individual from the federal government. ICFDD are licensed by the Illinois Department of Public Health and funded by Title XIX through the Illinois Department of Public Aid.

Intermediate Care Facility for the Developmentally Disabled 15 Beds or Less (ICFDD<15)

Living arrangements in the community for persons with disabilities, size is generally 8-15 adults, 18 years of age and older. Basic independent living skills and an off site vocational training or day program are emphasized.

International Symbol for Access

The symbol recognized locally, statewide, nationally and throughout the world to designate services, accessibility and accommodations for people with disabilities (i.e. handicapped parking, restrooms, methods of entrance and egress, telephones with amplifying devices).

Interpreter

A person who translates through sign language or other means verbal communication to persons who are deaf or persons who have a partial or severe hearing loss.

Language Disorders

A communication problem in comprehending, or expressing spoken language.

Lead Poisoning

A toxic condition caused by the ingestion of lead causing damage to the central nervous system and mental retardation. Generally occurs from lead based paint.

Specific Learning Disability

A disorder in the ability to learn effectively in respect to one's own potential when presented with an appropriate, regular instructional environment. The term specific learning disability is preferred over the more general term "learning disability" because it emphasizes that the disability affects only one or two areas of learning. (National Rehabilitation Association)

Least Restrictive Environment (LRE)

A concept used by (and upheld by the courts) professionals and others in the human services area to describe services, including housing, which should be provided in the most normal setting and atmosphere possible and "least restrictive" to a person's freedom.

Legally Blind

A term for visual impairment which generally establishes eligibility for special services. It is defined as vision of 20/200 in the better eye after correction or if vision does not exceed 20 degrees in the visual field.

Limited Mobility

A term generally used to refer to the inability of an individual to move about easily due to a physical disability. Can also refer to instances where there is a lack of accessible transportation thereby limiting mobility.

Local Education Agency

An administrative unit designated in federal and state laws concerning regular and special education. Unit is generally a school district, and has the legal responsibility for the

provision of education.

Long Term Care

A generic term to describe placement in congregate settings for longer than 30 days.

Low Incidence Disability

A term used to describe a disability which occurs on a less frequent basis than other disabilities. Prader Willi Syndrome, Tourette Syndrome, and Deaf/Blind are among low incidence disabilities.

Mainstreaming

A term used in special education which refers to the integration of disabled children/students into programs and courses of study attended by their non-disabled peers. "Least restrictive", is a concept to provide services whenever possible in settings which allow for participation among non-disabled persons.

Means Test

A criteria for determining eligibility of applicants for various human services programs. Criteria include income (i.e. employment, investments, Social Security, pension) and necessary living (rent, food) expenses.

Medicaid

Title XIX of the Federal Social Security Act regarding medical assistance programs, federally supported program administered by the Illinois Department of Public Aid. Eligible persons with disabilities may receive a range of services, for which the state is reimbursed by the federal government 50% of the total cost of service.

Medicaid Waiver Program

A program to finance home and community based services for persons with developmental disabilities. Services that can be covered under the waiver are case coordination, habilitation (includes day and residential programs) and respite care services. The purpose of the waiver program is to provide an alternative to higher cost institutional care in long term Medicaid funded settings for individuals 18 years of age and older with developmental disabilities.

Medicare

A health insurance program also under the Social Security Act. Provides for hospital insurance and other related health care care services.

Mental Age

A term used to express an individual's mental ability in terms of average chronological age of others.

Mental Illness

Term used to describe a person who has lost the social and/or vocational skills necessary to function independently. Negative, demeaning terms such as mentally deranged, deviant, maniac, crazy, lunatic, and mad are considered inappropriate and should be used only in direct quotations.

Mental Retardation

Is the preferred term for describing a person who, from birth, has developed at a rate significantly below average with an associated impairment in adaptive behavior. Can be categorized into four levels -- mild, moderate, severe and profound. Terms such as idiot, moron, mentally deficient/defective, imbecile, and feeble-minded are considered derogatory.

Multiple Handicap

This term refers to having more than one disability. It is more acceptable to say "disability" than "handicap".

Multiple Sclerosis (MS)

A progressive disease which affects the brain and spinal cord causing failure of the neurological system which may manifest eye problems, speech, some degree of paralysis and poor coordination.

Muscular Dystrophies

A series of muscle destroying disorders which vary in hereditary patterns, age of onset, muscles affected and rate of progression.

Neurological Impairments

A general term which refers to disorders of the nervous system that can impair normal functioning of the brain and nervous system.

Neuromuscular Diseases

A term which refers to disorders affecting the nerves and muscles.

Non-Ambulatory

A term used to describe the inability to move or walk independently.

Non-Categorical

A term used to refer to programs or philosophies which do not differentiate among disabilities or do not label individuals.

Non-Verbal

A term used to describe the inability to express language through speech. Does not mean that all language abilities are affected.

Nursing Home

A long term care facility that provides some level of nursing care for persons who are disabled, sick, infirm or require convalescence. Also known as an intermediate care facility, licensed by the Department of Public Health and funded by Title XIX of the Social Security Act through the Illinois Department of Public Aid.

Occupational Therapy (OT)

A rehabilitative process to enhance development or a return of muscular movements and coordination. Emphasis is placed on motor activities, coordination of movement and self help skills.

Ombudsman

An individual who advocates on behalf of another in resolving disputes or securing services.

Organic

A term generally used to describe a condition resulting from a disease or damage to an individual's body.

Orthopedic

A term which is generally used is describing a disability pertaining to bones, joints and muscles.

Outreach

Services or activities, beyond current or usual limits, to identify, treat and integrate into the service system persons who may "fall between the cracks," or who may be unaware or unable to access available services for persons with disabilities.

Paraplegia

Partial or total paralysis of the lower half of the body including both legs.

Paraprofessional

A term used to describe a trained aide/assistant who assists a professional person (i.e. teacher's aide, physician's assistant).

Pediatrician

A medical doctor who specializes in the branch of medicine dealing with the development, care, and diseases of children.

Personal Care Assistant

An individual who, under the supervision of a person with disabilities, performs or assists the individual with personal care and other tasks essential to independent living.

Phenylketonuria (PKU)

A hereditary condition in which the absence of an enzyme essential for digesting protein results in the build up of toxic substances. Without treatment through dietary means, can cause mental retardation. Illinois law requires mandatory screening of all newborns for PKU.

Physical Therapy (PT)

Treatment of disabilities by physical means, such as massage, exercise, water, light, heat and other mechanical devices.

Polio (Infantile Paralysis)

A condition which is caused by a virus that can result in partial or complete paralysis. No longer a serious major health problem due to the vaccine.

Prader-Willi Syndrome

A condition of unknown origin which is a dysfunction of the central nervous system. In infants, characteristics may include low birth weight, poor muscle tone, weak cry, poor

sucking reflex, lack of ability to control head or limbs and poor appetite. For adults, characteristics may include short stature (average height of five feet), lack of muscle tone, incomplete sexual development, diminished sense of pain, wondering or crossed eyes, and an uncontrollable appetite.

Prenatal

The time period prior to birth, generally when emphazing timely prenatal care to enhance pregnancy outcomes.

Prevalence

Term used to describe the frequency of a disability in relation to the total population of an area.

Proprietary or For-Profit

A facility operated on a for-profit basis, i.e., nursing homes or health related facilities operated as an income business.

Protection and Advocacy

A system of services that provides assistance to prevent or alleviate abuse, neglect or exploitation of persons with disabilities who are unable to protect their own interest. Advocacy services also mean intervention on behalf of a person with disabilities to protect his/her rights in seeking and obtaining services from public and private agencies.

Psychiatrist

A physician who specializes in the diagnosis and treatment of emotional problems and mental disorders.

Psychologist

An individual who is trained in the assessment and treatment of people with emotional, interpersonal or behavorial problems.

Public Hearings

A public forum that can be held locally, statewide or nationally to hear verbal and /or written testimony from interested persons on specific and/or a wide range of issues, such as education, housing, employment or rights.

Reasonable Accommodation

A term generally used when referring to adaptations of the work place to enable a person with disabilities to perform work. Accommodations could range from a ramp to more tech-

nical adaptations or equipment.

Rehabilitation

Process of assisting individuals with disabilities toward a desired level of functioning through education and (re)training. Services are often vocational or physical in nature.

Respite Services

A term generally used in describing time limited residential services outside an individual's home usually provided in a small living arrangements. In-home respite services may also be provided. Respite services are intended to provide relief for the primary care giver.

Right to Treatment

A concept or principle set forth (and upheld by the Courts) which is an accepted part of treatment of persons with disabilities that holds that these individuals are entitled to and a facility must provide treatment.

School Age

A term generally used in special education which means that an individual is entitled to special education and related services from 3 through 21 years of age.

Screening

A term used to describe abbreviated testing procedures in a variety of disciplines.

Seizure

A brief and temporary change in the brain's functioning; generally associated with epilepsy.

Severe Mental Retardation

Refers to a level or classification of mental retardation. Persons who are severely mentally retarded generally require lifelong supervision and services.

Sheltered Workshop

A term which generally describes a facility which offers services of a vocational nature for adults with disabilities. Can offer paid or unpaid employment in the workshop or through opportunities in the local community.

Sickle Cell Anemia (Sickle Cell Disease)

A chronic and inherited anemia which can cause unpredictable periods of severe pain in the joints, abdomen, spine and other parts of the body; pneumonia; bone infections; and jaundice.

Sign Language

A means of communication with or among persons who have a hearing impairment or other communication disorder. There are several forms of sign language: American Sign Language--a visual or gestural language with vocabulary and grammar different from standard English; Signed English--a system of a more grammatical and word-for-word method; and Fingerspelling--the use of 26 different handshapes to represent the letters of the alphabet to spell out words.

Skilled Nursing Facility (SNF)

A facility, or distinct part of an institution (e.g. hospital or nursing home), that is licensed to provide inpatient care for persons requiring skilled nursing services for a chronic disease or convalescence over a prolonged period of time.

Social Security Disability Insurance (SSDI)

Federally supported financial entitlement program for persons with disabilities or their family members. Children 18 years of age or older who were disabled prior to age 22 can also receive benefits when either parent retires or dies.

Spastic

A term used to describe a muscle with sudden abnormal involuntary spasms. It is not appropriate for describing a person with cerebral palsy--muscles are spastic, not people. (National Rehabilitation Association)

Special Education and Related Services

Specially designed instruction, at no cost to the parent, to meet the unique needs of a handicapped child, including classroom instruction, instruction in physical education, home instruction, and instruction in hospitals and institutions.

Related services means transportation and such developmental, corrective, and other supportive services as are required to assist a handicapped child to benefit from special education. This includes speech pathology and audiology; psychological services; physical and occupational therapy; recreation; early identification and assessment of disabilities in children; counseling services; and medical services for diagnos-

tic or evaluation purposes. The term also includes school health services, social work services in schools, and parent counseling and training (Education of the Handicapped Act, P.L. 94-142).

Special Habilitation (SHP)

Services of a time limited nature for persons who require intensive habilitation or crisis behavior management to prevent extrusion from the home or to secure placement in a less restrictive living arrangement. This service is funded through the Illinois Department of Mental Health and Developmental Disabilities' Purchase of Care Program.

Special Olympics

Events at a local, state and national level to offer to persons with disabilities a wide range of competitive games and other sports. These events are largely staffed by volunteers.

Special Recreation

Specialized recreational services that are provided through park districts to persons with disabilities. Special Recreation Associations are made up of consolidated communities in local areas that sup-port these services.

Specialized Living Center (SLC)

Offers a structured program for adults, 18 years of age and older with disabilities who require training in self help and prevocational skills. Day program is provided off site from the residential setting. There are five SLC facilities in the state, each serving from 64-100 persons. Facilities are licensed by the Illinois Department of Public Health as ICFDD and are funded through the Illinois Department of Public Aid.

Speech Disorders

A term used to describe a condition which interferes with communication. A disorder that may affect voice, articulation or fluency.

Spina Bifida

A term which means an incomplete closure in the spinal column with varying degrees of severity. Frequently this condition causes paralysis of the lower extremities. Also known as myelomeningocele.

For more information, contact:

-- Spina Bifida Hotline
(1-800-621-3141)

Spinal Cord Injury

A person with a spinal cord injury has "a lesion of the spinal cord resulting from an injury or disease that usually results in paralysis of certain parts of the body, the loss of sensation, the loss of bowel and bladder control." (National Spinal Cord Injury Foundation)

For more information, contact:

-- National Spinal Cord Injury Hotline
(1-800-256-3456)

Supplemental Security Income (SSI)

Federally supported and administered financial entitlement program for persons with disabilities. Eligible persons receive income maintenance support based upon need.

Supported Employment Program (SEP)

Competitive work in integrated work settings for individuals with severe handicaps for whom competitive employment has not traditionally occurred or for individuals for whom competitive employment has been interrupted or intermittent as a result of severe disability and who need ongoing support services to perform such work.

Supported Living Arrangement (SLA)

Support and direction provided to adults with disabilities who are fairly independent and require only minimal supervision.

Supported Work

Program wherein individuals with disabilities receive evaluation, transition services and time-limited employment and follow along. This program is provided by the Department of Rehabilitation Services.

Targeted Jobs Tax Credit Program

Federal program to provide an incentive for employers to hire individuals who are vocational rehabilitation referrals. Employer can receive a federal tax credit for employing these individuals (as well as other identified groups).

Telecommunications Devices for the Deaf (TDD's)

Electronic devices which provide for video or hard copy printed communication across telephone lines. These are used by persons with hearing impairments.

Therapeutic Recreation

Therapeutic recreation is the use of recreation services to improve or maintain physical, mental, emotional, and/or social functioning and assist individuals in expressing independent lifestyles.

Tourette Syndrome (TS)

A neurological disorder characterized by involuntary muscular movements (i.e. excessive blinking, sniffing, twisting and bending body), uncontrollable vocal sounds (i.e. cough, sniff, grunt, bark, shout) and inappropriate words (i.e. involuntary obscenities or repeating words of other people).

Trainable

A term used in special education which refers to the classification of a child's intellectual development, mental capacity, academic achievement and adaptive behavior as moderate, severe to profound mental retardation.

Tuberous Sclerosis

Tuberous Sclerosis is a genetic disease characterized by one of its most common symptoms in its most severe form--the hardening (sclerosis) of swellings (tubers) or tumors.

Visual Impairments (Blind and Visually Impaired)

Terminology generally used to describe a variety of conditions which mean that a person has limited or no vision.

SECTION III

ILLINOIS EXECUTIVE AND ELECTIVE OFFICES, STATE AGENCIES, AND COMMISSIONS

BUREAU OF THE BUDGET (BOB)

Created within the Executive Office of the Governor, the Bureau assists the Governor in the annual submission of the state's fiscal year budget to the Illinois General Assembly. The Bureau, with the assistance of all state agencies, commissions, boards and institutions prepares the recommended budgets for each of the preceding, including, anticipated revenue, estimates of receipts, and expenditures for the succeeding fiscal year. The Bureau evaluates programs proposed by state agencies in terms of goals, costs, relative priorities, programs' accomplishments, and the coordination, development and implementation of state programs.

Organizationally, the Bureau is divided into 8 divisions. The Division of Health and Human Services includes the majority of agencies listed in this section.

For more information, contact:

-- Illinois Bureau of the Budget
602 Stratton Office Building
Springfield, IL 62706
(217)782-5886

DEPARTMENT ON AGING (DOA)

The Department on Aging was created by state statute in 1973 for the purpose of improving the quality of life for Illinois' older citizens. It is the single state agency in Illinois authorized to receive and dispense Federal Older Americans Act funds to area agencies on aging, which in turn distribute the funds to community-based service providers. The department works with area agencies in planning a comprehensive system of services that ranges from nutrition, transportation and employment assistance to senior center facilities and information and referral services. The department also administers a state-wide community care program which utilizes state funding to provide homemaker, chore/housekeeping and adult day care services. The program is specifically designed to prevent premature or inappropriate institutionalization. Case management services are provided to clients by over 60 case coordination units serving as health and social service agencies for older people in need of long-term care.

For more information, contact:

-- Department on Aging
100 W. Randolph, Suite 11-900
Chicago, IL 60601
(312)793-2914

or

-- Department on Aging
421 E. Capitol, 1st Floor
Springfield, IL 62706
(217)785-2870
Toll Free 1-800-252-8966

DEPARTMENT OF CHILDREN AND FAMILY SERVICES (DCFS)

The Department of Children and Family Services administers a variety of programs designed to protect children and strengthen family life through eight regional offices and 80 field offices. In response to the Abused and Neglected Child Reporting Act, the department maintains a toll-free, 24-hour hotline at the DCFS computerized State Central Register in Springfield. It is used by concerned citizens and those required by law to report cases of suspected child abuse or neglect to DCFS. The department provides directly, or purchases from private agencies, family counseling, protective services for abused or neglected children, foster family care, help to unwed parents, adoption services, home-maker services, institutional care for disturbed youngsters, and day care. The department operates a network of emergency shelter care facilities in Cook County. DCFS also administers a grant program to encourage organizations to develop community-based networks to serve troubled teens and their families.

For more information, contact:

-- Department of Children and Family Services
100 W. Randolph 6th, Suite 6-200
Chicago, IL 60601
(312)917-4650

or

-- Department of Children and Family Services
623 E. Monroe
Springfield, IL 62701
(217)785-2509

GUARDIANSHIP AND ADVOCACY COMMISSION (GAC)

The Guardianship and Advocacy Commission was created to safeguard the rights and to provide legal counsel and representation to persons with disabilities. The legislation also created an Office of State Guardian for persons with disabilities. The Commission is made up of 11 members who are appointed by the Governor, subject to the advice and consent of the Senate. There are 7 regional Human Rights Authorities in the state, each made up of 9 members appointed by the Commission. Each Authority which receives a complaint alleging violation of an individual's right may investigate such compliant and may initiate investigations on its own initiative in the region of its jurisdiction.

Through 7 regional offices in the state, the Commission also provides advocacy services for persons with disabilities, who believe their rights have been abridged, denied or violated.

For more information, contact:

-- Guardianship and Advocacy Commission
123 West Madison, Fl 18
Chicago, IL 60602
(312)793-5900

or

-- Guardianship and Advocacy Commission
305 Stratton Building
Springfield, IL 62706
(217)785-1540

DEPARTMENT OF HUMAN RIGHTS (DHR)

The Department of Human Rights administers the Illinois Human Rights Act which prohibits discrimination in employment, real property transactions, access to financial credit and public accommodations. Any persons with a handicap or other persons who believe they may have been discriminated against can file a complaint with the Department.

For more information, contact:

-- Department of Human Rights
State of Illinois Center
100 W. Randolph, Suite 10-100
Chicago, IL 60601
(312)917-6245

or

-- Department of Human Rights
619 Stratton Building
Springfield, IL 62706
(217)785-5100

OFFICE OF ILLINOIS ATTORNEY GENERAL
DISABLED PERSONS ADVOCACY DIVISION

Established in 1983, the Division represents persons with disabilities in the State in terms of disability rights issues. The Division has two advisory groups; the Consumers Task Force, representatives of persons with expertise in the fields of mental health, developmental disabilities and the physically handicapped. The Lawyers Advisory Council is representative of attorneys who have expertise in one or more areas of disability law.

Staff are located throughout the State in regional offices of the Attorney General.

For more information, contact:

-- Office of Illinois Attorney General
174 W. Randolph, Suite 2
Chicago, IL 60601
(312)793-5109
(312)793-2852 (TDD)

or

-- Office of Illinois Attorney General
500 S. Second
Springfield, IL 62701
(217)782-2490
(217)785-2771 (TDD)

DEPARTMENT OF MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES (DMHDD)

The Department of Mental Health and Developmental Disabilities supports a network of 400 community-based programs which provide residential care, day training, support services, outpatient and crisis services for persons who are mentally ill or developmentally disabled. The department currently operates 23 residential settings for persons who are mentally ill and developmentally disabled, and three research and training institutes. The department is emphasizing the expansion of a wide range of community services as alternatives to institutionalization, thus increasing the capacity for persons with disabilities to remain at home or in independent living arrangements. If persons cannot be adequately cared for in these programs, support is provided through community-

based or state-operated residential care.

For more information, contact:

-- Department of Mental Health and Developmental Disabilities
State of Illinois Center
100 W. Randolph Suite 6-400
Chicago, IL 60601
(312)917-2735

or

-- Department of Mental Health and Developmental Disabilities
401 Stratton Building
Springfield, IL 62706
(217)782-2753

DEPARTMENT OF PUBLIC AID (DPA)

The Department of Public Aid administers federally-aided programs for families with dependent children (AFDC), the medical assistance program, the USDA food stamp program, and the social services program. The department operates a general assistance program in Chicago and provides state funds to qualifying local townships in downstate counties for general assistance. Additionally, the department is responsible for the collection of child support payments from parents ordered to pay such support. Child support and parent locator services are provided to recipients of public assistance and are also available free of charge to other Illinois residents. Other services include: support services to teen and parents, funding for refugees and victims of domestic violence.

For more information, contact:

-- Department of Public Aid
624 S. Michigan Avenue, Rm. 1300
Chicago, IL 60605
(312)793-4706

or

-- Department of Public Aid
316 South 2nd Street
Springfield, IL 62762
(217)782-6716

DEPARTMENT OF PUBLIC HEALTH (DPH)

The Department of Public Health is composed of four offices and an administrative unit. The Administrative Unit provides managerial and staff services necessary to support programs through the department as well as legal services, internal audit and public information activities. The Office of Health Services is responsible for administering the department's health care and disease control programs; the Office of Health Regulation administers programs designed to ensure quality care in all health facilities operating in Illinois and controls or eliminates environmental health hazards; the Office of Health Finance monitors health care to assure that state-purchased care is obtained at a reasonable cost. DPH licenses many residential facilities for persons with disabilities. In addition, a list of facilities that are in serious violation of state regulations is maintained. The department maintains eight regional offices which provide consultation and direct services to make programs more accessible to area residents.

For more information, contact:

-- Department of Public Health
100 W. Randolph, Suite 6-600
Chicago, IL 60601
(312)917-2793

or

-- Department of Public Health
535 W. Jeffersons St., 4th Floor
Springfield, IL 62761
(217)782-2033

DEPARTMENT OF REHABILITATION SERVICES (DORS)

The Department of Rehabilitation Services (DORS) is the state's lead agency serving individuals with disabilities of all ages. DORS provides rehabilitation services to eligible persons through a variety of programs, including: Vocational Rehabilitation; Home Services; Community Services for the Visually Handicapped; Illinois Visually Handicapped Institute; Bureau of Disability Adjudication Services; Illinois Childrens' School and Rehabilitation Center (ICSRC); Illinois School for the Visually Impaired (ISVI) and Illinois School for the Deaf (ISD). ICSRC, ISVI, and ISD are fully accredited, residential schools offering elementary and secondary education programs and support services to children and youth with disabilities.

For more information, contact:

-- Department of Rehabilitation Services
100 W. Randolph, Suite 8-100
Chicago, IL 60601
(312)917-2920
or

-- Department of Rehabilitation Services
623 E. Adams
Springfield, IL 62705
(217)785-0218

SECRETARY OF STATE
SENIOR CITIZENS AND HUMAN RESOURCES DEPARTMENT

The Secretary of State's Senior Citizens and Human Resources Department offers various services to Illinois citizens with disabilities.

Handicapped and personalized handicapped licensed plates and parking cards are available for cars, pickup trucks and vans. These specialized plates are affixed with the international symbol for accessibility and allows parking for people with disabilities. Persons with disabilities may also receive identification cards; and drivers and non drivers can obtain photo identification cards.

A 3 hour curriculum entitled "Law Enforcement and the Disabled" is available from the Senior Citizens and Human Resources Department. The training and inservice curriculum was developed for police recruits, police and law enforcement personnel to provide guidance on appropriate interactions with persons with disabilities.

Specialized services are available to persons with visual impairments and physical disabilities in Illinois Public Libraries. Magazines and books can be made available on records, cassettes or in braille or other adaptive equipment. There is no charge for these services.

For more information, contact:

-- Secretary of State
Senior Citizens and Human Resources Department
450 Centennial Building
Springfield, IL 62756
1-800-252-2904 (Voice or TDD)

ILLINOIS STATE BOARD OF EDUCATION (ISBE)

The Illinois State Board of Education sets educational policies and guidelines for public and private schools, preschool through grade 12, as well as for adult and vocational education. The State Board is also the designated State education agency to ensure compliance with Public Law 94-142, the Education of the Handicapped Act by local school districts. The State Board consists of 17 members appointed by the Governor with the consent of the Senate. Members serve six-year terms, with each limited to two consecutive terms.

Other responsibilities include providing educational leadership to local school districts; insuring that schools meet minimum standards for educational programs, personnel and business management practices; providing local schools with expert help in curriculum and management; disbursing more than $2 billion in state and federal funds each year; and administering a policy of equal education opportunity for all.

For more information, contact:

-- State Board of Education
100 W. Randolph, Suite 14-300
Chicago, IL 60601
(312)793-2220

or

-- State Board of Education
100 North First Street
Springfield, IL 62777
(217)782-9560

UNIVERSITY OF ILLINOIS, DIVISION OF SERVICES FOR CRIPPLED CHILDREN (DSCC)

The Division of Services for Crippled Children (DSCC) is the designated Crippled Children's Agency for the State of Illinois. Federal Statutes and Regulations of Title V and Title XVI of the Social Security Act as amended by the Maternal and Child Health Services Block Grant P.L. 97-35 mandate the specialized services delivered by the Division. The Illinois Department of Public Health administers the federal grant funds; an interagency agreement within the Division allows for the disbursement of these monies to the Division. In Illinois, the Division is administered by the University of Illinois, Board of Trustees. The scope of services are offered statewide to children with special health care needs birth through twenty-one (0-21) years of age. A recipient of service must meet two eligibility criteria. The second, the financial status of the parent or guardian.

For more information, contact:

-- University of Illinois
Division of Services for Crippled Children
2040 Hill Meadows Drive, Suite A
Springfield, IL 62702
(217)793-2350

SECTION IV

Relevant Federal Statutes

Title XIX (Medicaid) of the Social Security Act of 1935 is a federally funded medical assistance program providing funding for the care and treatment of persons of low income with serious medical problems.

Title XX of the Social Security Act a federal program providing funding of such services, as day care, special living arrangements, employment programs, counseling, information and referral. (Known as the Social Services Block Grant)

Title XVI Supplementary Security Income (SSI) is a federally administered income assistance program. Recipients of SSI must be 65 or older, or blind, or disabled and have incomes and assets below a certain level regardless of work history. SSI benefits are unrestricted direct cash payments to the individual. There is no limit to the length of time an individual may receive SSI benefits as long as eligibility criteria are met.

PUBLIC LAW (P.L.) 99-643, Employment Opportunities for the Disabled Act makes section 1619 of the Social Security Act permanent. Allows needy individuals who are blind, elderly and disabled who work to retain a portion of their Supplemental Security Income (SSI) and Medicaid eligibility.

PUBLIC LAW (P.L.) 98-527 Developmental Disabilities Act of 1984 provides federal funding for planning, services, and protection and advocacy for persons with severe and chronic disabilities whose needs cannot be met by generic community services. In addition, this Act provides for interdisciplinary training of professionals, research activities, and special project grants designed to enhance service delivery. This is the enabling legislation creating the Governor's Planning Council on Developmental Disabilities and the Protection and Advocacy, Inc.

PUBLIC LAW (P.L.) 94-142 Education of the Handicapped Act guarantees a free, appropriate public education for all handicapped children between the ages of three and twenty-one. It includes provisions for special education, related services, and vocational education. The law contains several safeguards to assure the rights and protection of handicapped students and their parents. One of the most important safeguards is the Individualized Education Program (IEP). The IEP must be developed and updated annually by a team which includes the parent(s), the teacher and other school representative(s). Career development objectives must be included in the IEP.

PUBLIC LAW (P.L.) 99-457, Education of the Handicapped Act Reauthorization Amendments of 1986 continues the Act for the next five years; provides for early intervention services for infants and toddlers birth to two years of age; new preschool grant for three-five year olds; and extends the authority for other discretionary programs. Other discretionary programs could include services for deaf/blind children and youth; regional resources and federal centers; post-secondary education program; and secondary education and transition services.

PUBLIC LAW (P.L.) 89-313 Elementary and Secondary Education Act provides federal funds for more severely handicapped school aged special education children. This funding source provides a higher per child amount for high cost special education children. Students cannot be claimed for both the P.L. 94-142 and P.L. 89-313 funding sources.

PUBLIC LAW (P.L.) 93-112 The Rehabilitation Act of 1973 provides for the availability of grant monies to the State to fund vocational rehabilitation services for persons who are severely disabled. It also guarantees equal opportunity for comprehensive and coordinated programs of vocational rehabilitation and independent living.

> Section 503 of the Rehabilitation Act requires that every employer doing business with the federal government, under a contract of $2,500 or more, must take affirmative action to recruit, hire, train and promote handicapped individuals.
>
> Section 504 of the Rehabilitation Act states that no otherwise qualified handicapped individual in the United States, shall solely be reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

PUBLIC LAW (P.L.) 99-506, Rehabilitation Act Amendments of 1986 reauthorizes the Act for five years placing a major focus upon supported employment for individuals with severe disabilities. Supported employment is declared an acceptable outcome for employability; the Act also authorizes grants for supported employment and transitional planning services for youth.

PUBLIC LAW (P.L. 95-602) Disabilities Assistance and Bill of Rights Act of 1978, (as amended by P.L.98-527) assists states in the provision of a comprehensive system of services to insure developmentally disabled persons receive the services necessary to achieve maximum potential as well as services which insure protection of their legal and human rights.

Relevant State Statutes

PUBLIC ACT 80-144 Mental Health and Developmental Disabilities Code provides for the rights of recipients who are mentally ill or developmentally disabled who have received or are receiving treatment or habilitation from any mental health or developmental disabilities facilities, or from a person who provides such services. Also sets forth procedures for the admission, transfer and discharge of persons who are mentally ill or developmentally disabled.

PUBLIC ACT 80-1508 Mental Health and Developmental Disabilities Confidentiality Act protects the confidentiality of records and communication of persons who are recipients of mental health or developmental disability services. Contents of a person's record cannot be shared with others without the written permission of the person.

PUBLIC ACT 82-183 Community Services Act facilitates the establishment of community services for persons who are mentally ill, developmentally disabled, alcohol dependent, or addicted. States that services should be established in all areas of the State in the following service categories -- prevention; client assessment and diagnosis; case coordination; crisis and emergency; treatment, habilitation and support; and community residential alternatives to institutional settings.

PUBLIC ACT 81-223 Nursing Home Care Reform Act of 1979 provides for the rights of residents of nursing homes including skilled nursing and intermediate care facilities. Any resident or his/her representative may file a complaint with the Illinois Department of Public Health who investigates and makes a determination that a facility is or is not in violation of the Act.

The School Code of Illinois governs the establishment, operation and maintenance of public schools, providing for the transportation of and scholarships in institutions of higher learning for students of all schools. Also governs special education and related services and special education facilities for handicapped children.

PUBLIC ACT 84-948 Environmental Barriers Act created to eliminate environmental barriers in public facilities and multistory housing units. Barrier includes any feature of the environment which restricts access to or use of the environment by a person with a physical, mental or communications disability.

Illinois Election Code provides that any voter who requires assistance to vote by reason of blindness, physical disability or inability to read, write or speak English shall be provided assistance by 2 election judges. Also allows the election authority to conduct voting at the site of a nursing home for persons who have disabilities who are unable to go to polling places.

PUBLIC ACT 84-734 allows the Secretary of State to issue (upon request) special license plates with the international accessibility symbol so as to be easily recognizable as automobiles driven by or for handicapped persons. The individual requesting special plates must submit a statement certified by a licensed physician as to having a physical disability or provide documentation of a disability through issuance of a Illinois Disabled Person Identification Card.

This Act also prohibits unauthorized use of parking places reserved for handicapped persons. Any persons found in violation of this, may be subject to a fine and/or other costs associated with the removal and storage of the vehicle.

SECTION V

NATIONAL ADVOCACY AND NON-GOVERNMENTAL AGENCIES AND ORGANIZATIONS

American Association on Mental Deficiency
1719 Kalorama Road, N.W.
Washington, D.C. 20009
202/387-1968

American Council of the Blind
1010 Vermont Avenue, N.W.
Suite 1100
Washington, D.C. 20005
202/393-3666

American Foundation for the Blind
15 West 16th Street
New York, NY 10011
212/620-2000

Council for Exceptional Children
1920 Association Drive
Reston, VA 22091
703/620-3660

Cystic Fibrosis Foundation
6000 Executive Boulevard
Rockville, MD 20852
1-800-344-4823

Federal of the Handicapped Inc.
211 West 14th Street
New York, NY 10011
212/242-9050

National Association for Children and Adults with Learning Disabilities
4156 Library Road
Pittsburgh, PA 15234
412/341-1515

National Association for Down Syndrome
Box 4542
Oak Brook, IL 60521
312/325-9112

National Association for Retarded Citizens
P.O. Box 6109
2501 Avenue J
Arlington, TX 76006
817/640-0204

National Association for Sickle Cell Disease, Inc.
4221 Wilshire Boulevard,
Suite 360
Los Angeles, CA 90010-3503
213/936-7205

National Down Syndrome Congress
1800 Dempster Street
Park Ridge, IL 60068-1146
312/823-7550

National Easter Seal Society
2023 West Ogden Avenue
Chicago, IL 60612
312/243-8400
312/243-8880 (TDD)

National Federation of the Blind
1800 Johnson Street
Baltimore, MD 21230
301/659-9314

National Head Injury Foundation
333 Turnpike Road
South Borough, MA 01772
617/879-7473

National Muscular Dystrophy Association
810 7th Avenue
New York, NY 10019
212/586-0808

National Tuberous Sclerosis
Association
Box 612
Winfield, IL 60190
312/668-0787

National Society for Children
and Adults with Autism
1234 Massachusetts Avenue N.W.
Suite 1017
Washington, D.C. 20005
202/783-0125

National Spinal Cord Injury
Association
1032 S. LaGrange Road
LaGrange, IL 60525
312/352-6223

President's Committee on
Employment of the Handicapped
1111 20th Street N.W.
Washington, D.C. 20036
202/653-5044

President's Committee on
Mental Retardation
330 Independence Avenue S.W.
Room 4723
North Building
Washington, D.C. 20201
202/245-7634

Spina Bifida Association
of America
1700 Rockville Pike, Suite 540
Rockville, MD 20852
301/770-7222
1-800-621-3141

The Association for Persons
with Severe Handicaps
7010 Roosevelt Way N.E.
Seattle, WA 98115
206/523-8446

United Cerebral Palsy
Association, Inc.
66 E. 34th Street
New York, NY 10016
212/481-6300

STATE ADVOCACY AND NON-GOVERNMENTAL AGENCIES AND ORGANIZATIONS

American Association on Mental Deficiency
Trinity School
Route 2, Gougar Road
Joliet, IL 60432
815/485-6197

American Foundation for the Blind
20 North Wacker Drive
Suite 1938
Chicago, IL 60606
312/269-0095

Arthritis Foundation - Illinois Chapter
79 W. Monroe Street
Chicago, IL 60603
312/782-1367

Association of Human Service Providers for Black Residents of Illinois
415 S. Kilpatrick
Chicago, IL 60644
312/261-2252

The Association for Persons with Severe Handicaps
IL State Board of Education
100 North First, E 216
Springfield, IL 62777
217/782-5333

Association for Retarded Citizens of Illinois
700 South Federal, Suite 123
Chicago, IL 60605
312/922-6932

Chicago Northern Illinois Chapter - National Multiple Sclerosis Society
600 South Federal, Suite 204
Chicago, IL 60605
312/922-8000

Coalition of Citizens with Disabilities in Illinois
1 W. Old Capitol Plaza
Suite 402
Springfield, IL 62701
217/522-7016 Voice/TDD

Coordinating Council for Handicapped Children
20 E. Jackson Blvd. Rm 900
Chicago, IL 60604
312/939-3513

Committee to Combat Huntington's Disease, Inc.
2729 W. Berchwood Avenue
Chicago, IL 60645
312/420-4542

Congress of Organizations for Physically Handicapped
2030 Irving Park Road
Chicago, IL 60618
312/477-1813

Council for Disability Rights
343 S. Dearborn
Chicago, IL 60604
312/922-1092

Cystic Fibrosis Foundation
6 N. Michigan Avenue
Suite 414
Chicago, IL 60602
312/236-4491

Easter Seal Society of IL for Crippled Children and Adults
2715 S. 4th Street
Box 1767
Springfield, IL 62705
217/525-0398

Epilepsy Services of Chicago
22 W. Monroe, Suite 1501
Chicago, IL 60603
312/332-4107

Fiesta Educativa
1850 W. 21st Street
Chicago, IL 60608
312/427-4616

Myasthenia Gravis Foundation
53 W. Jackson, Suite 920
Chicago, IL 60604
312/427-6208

Tourette Syndrome Assoc. Greater Chicago Region
5102 Oakton, Suite 117
Skokie, IL 60077
312/675-2121

Illinois Alliance for Exceptional Children & Adults
2005 Clover Lane
Champaign, IL 61821
217/359-5345

Illinois Alliance for the Mentally Ill
R.R. #1, Box 21
Dietrich, IL 62424
312/297-9966

Illinois Association of Adults with Learning Disabilities
3227 S. Fifth Street
Springfield, IL 62703
217/529-1023

Illinois Association of Community Mental Health Agencies
730 E. Vine Street
Springfield, IL 62703
217/528-5338

Illinois Association of the Deaf
180 Boulder Hill Pass
Aurora, IL 60538

Illinois Association of Rehabilitation Facilities
206 S. Sixth Street
Springfield, IL 62701
217/753-1190

Illinois Council for Exceptional Children
1827 Valencia
Pekin, IL 61554
309/347-8102

Illinois Council for Children with Behavior Disorders
P.O. Box 340
Jacksonville, IL 62651

Illinois Parents of Deaf/ Blind
4010 N. Brandywind Drive
Apt. 512
Peoria, IL 61614
309/686-1946

Illinois Prader Willi Parent Group
2836 Arlington Avenue
Highland Park, IL 60035
312/433-2836

Illinois Society for Autistic Citizens
2200 S. Main, Suite 317
Lombard, IL 60148
312/691-1270

Illinois Spina Bifida Association
1525 Ogden Avenue
Downer's Grove, IL 60515
312/960-2426

Land of Lincoln Epilepsy Association
1415 E. Jefferson Street
Springfield, IL 62703
217/789-2258

Muscular Dystrophy Assoc.
of America
8700 Waukegan Road
Suite 228
Morton Grove, IL 60053
312/965f-8900

March of Dimes Birth Defects
Foundation
53 West Jefferson Blvd.
Chicago, IL 60604
312/407-4007

Parents Association for
Handicapped Citizens
P.O. Box 8723
Rolling Meadows, IL 60008
312/837-5185

Protection and Advocacy, Inc.
175 West Jackson
Suite A-2101
Chicago, IL 60604
312/341-0022

Special Education Parents
Alliance
1100 South Main Street
Lombard, IL 60148
312/790-3060

United Cerebral Palsy - IL
3 W. Old State Capitol Plaza
Suite 204-B
Springfield, IL 62701
217-789-0390

Voice of the Retarded
P.O. Box 1395
Palatine, IL 60078-1395

SECTION VI

ACRONYMS

AAMD	American Association on Mental Deficiency
ACDD	Accreditation Council for Services for Developmentally Disabled Persons
ACLD	Association for Children with Learning Disabilities
ADD	U.S. Administration on Developmental Disabilities
ARC/I	Association for Retarded Citizens, Illinois
BOB	Bureau of the Budget
CAP	Client Assistance Program
CARF	Commission on Accreditation of Rehabilitation Facilities
CEC	Council for Exceptional Children
CF	Cystic Fibrosis
CLF	Community Living Facility
CP	Cerebral Palsy
DCFS	Department of Children and Family Services
DHHS	U.S. Department of Health and Human Services
DMHDD	Department of Mental Health and Developmental Disabilities
DOA	Department on Aging
DORS	Department of Rehabilitation Services
DPA	Department of Public Aid
DPH	Department of Public Health
DSCC	Division of Services for Crippled Children
DD	Developmental Disabilities/Developmentally Disabled
ED	Emotionally Disturbed
EFA	Epilepsy Foundation of America

EMH	Educable Mentally Handicapped
GAC	Guardianship and Advocacy Commission
HI	Hearing Impaired
HIP	Home Individual Placement
IARF	Illinois Association of Rehabilitation Facilities
ISAC	Illinois Society for Autistic Citizens
ISBE	Illinois State Board of Education
ICFDD	Intermediate Care Facility for the Developmentally Disabled
ICF/MR	Intermediate Care Facility for the Mentally Retarded
IEP	Individual Education Plan
IHP	Individual Habilitation Plan
IWRP	Individual Written Rehabilitation Plan
LD	Learning Disability
LEA	Local Education Agency
LRE	Least Restrictive Environment
MD	Muscular Dystrophy
MR	Mental Retardation
MS	Multiple Sclerosis
OH	Orthopedically Handicapped
OHDS	U.S. Office of Human Development Services
OSERS	U.S. Office of Special Education and Rehabilitation Services
OT	Occupational Therapy
P&A	Protection & Advocacy, Inc.
PCA	Personal Care Assistant
PT	Physical Therapy

RSA	U.S. Rehabilitation Services Administration
RT	Recreation Therapy
SLD	Specific Learning Disability
SLC	Specialized Living Facility
SNF	Skilled Nursing Facility
SNF/PED	Skilled Nursing Facility for Pediatrics
SSDI	Social Security Disability Income
SSI	Supplemental Security Income
SEP	Supported Employment Program
SLA	Supported Living Arrangement
ST	Speech Therapy
TMH	Trainable Mentally Handicapped
TDD	Teletype for Persons Who Are Deaf (TTY also used)
UCP	United Cerebral Palsy
VI	Visually Impaired

SECTION VII

TOLL FREE NUMBERS

Aging	
1-800-252-8966	Department on Aging (Illinois)
Alzheimers	
1-800-621-0379	Alzheimer's Disease and Related Disorders
1-800-572-6037	Alzheimer's Disease (Illinois)
Cystic Fibrosis	
1-800-344-4823	National Cystic Fibrosis Foundation (Maryland)
Diabetes	
1-800-223-1138	National Juvenile Diabetes Assoc. (New York)
Disability	
1-800-233-1222 1-800-833-3232(TDD)	AT&T National Special Needs Center
1-800-526-7234	Job Accommodation Network (West Virginia)
1-800-638-0742	Hill-Burton Free Hospital Care (Maryland)
1-800-368-5779	Medicare/Medicaid Hotline (Maryland)
1-800-248-2253	National Organization on Disability (Washington, D.C.)
1-800-346-2742	National Rehabilitation Information Center (Also ABLEDATE) (Washington, D.C.)
Down Syndrome	
1-800-221-4602	National Down Syndrome Society (New York)
Dyslexia	
1-800-222-3123	Orton Dyslexia Society

Education

1-800-345-8324	Center for Special Education Technology (Virginia)
1-800-848-4815	ERIC Clearinghouse on Adult Career & Vocational Education (Ohio)
1-800-638-9675	National Committee for Citizens in Education
1-800-421-8711	National Information Center for Educational Media (New Mexico)
1-800-544-3284	HEALTH National Clearinghouse on Post Secondary Education for Handicapped (Washington, D.C.)
1-800-222-1473	Eckerd Foundation Wilderness Camps (Florida)

Epilepsy

1-800-EFA-1000	Epilepsy Foundation of America (Washington D.C.)
1-800-426-0660	Epilepsy Information Line (Washington)

Health

1-800-336-4797	National Health Information Clearinghouse (Virginia)
1-800-638-6833	National Second Surgical Opinion Program (Maryland)

Hearing Impairment

1-800-237-6213	Captioned Films for the Deaf
1-800-468-9211	Center for Deaf
1-800-424-8576	Hearing Helpline - Better Hearing Institute (Washington, D.C.)
1-800-638-8255	National Association for Speech and Hearing (Maryland)
1-800-221-2483	National Center for Stuttering (New York)
1-800-521-5247	National Hearing Aid Society (Michigan)
1-800-352-8888	Tripod Service for Hearing Impaired (California)

Physical Disability

1-800-221-6827	National Easter Seal Society (New York)
1-800-621-3141	Spina Bifida Hotline (Illinois)

1-800-237-5055	Shriners Hospital for Crippled Children (Florida)
Spinal Injury	
1-800-526-3456	National Spinal Cord Injury Hotline (Minnesota)
State	
1-800-433-8848	Coalition of Citizens with Disabilities
1-800-252-8966	Department on Aging
1-800-25ABUSE	Department of Children & Family Services
1-800-233-3425	Department of Rehabilitation Services
1-800-641-3929	Client Assistance Program (Answers questions related to rehabilitation services)
1-800-233-DIAL	Disabled Individual Assistance Line (General information regarding DORS services)
1-800-252-4343	Department of Public Health - Long Term Care Facility Complaint Hotline
1-800-JOBS-NOW	Job Placement Employment Services for Employers
1-800-447-4221	ABLEDATA - Information and Resource Hotline
1-800-468-9211	Center for Deaf (Third party message relay system for persons with hearing impairments)
1-800-328-3000	General Information
1-800-252-2904	Secretary of State, Senior Citizens and Human Resources Department
1-800-252-8980	Secretary of State, Vehicle Services Department
1-800-637-8856	Social Security Applicant Assistance Line (SSI/SSDI federal)
Visual Impairment	
1-800-424-8567	National Library for Blind & Physically Handicapped (Washington, D.C.)
1-800-323-4238	Hadley School (Illinois)
1-800-424-8666	American Council of the Blind, Inc. (Washington, D.C.)
1-800-638-2300	Retinitis Pigmentosa (A Foundation Fighting Blindness) (Maryland)
1-800-638-7518	Job Opportunities for the Blind

If you have questions or would like additional information, please contact:

Illinois Governor's Planning Council on Developmental Disabilities

840 South Spring Street
Springfield, IL 62704
217/782-9696 Voice or TDD

or

State of Illinois Center
100 W. Randolph 10-601
Chicago, IL 60601
312/917-2080